

# **EXHIBIT C**

## **MINUTES**

### **LEGISLATIVE TASK FORCE ON SICKLE CELL DISEASE**

**Wednesday, October 3, 2012**

**10:30 a.m.**

**Room 272, State Capitol**

**Little Rock, Arkansas**

The Legislative Task Force on Sickle Cell Disease met Wednesday, October 3, 2012, in Room 138 of the State Capitol in Little Rock, Arkansas. The following members attended: Ms. Mary Gupton, Mr. Germaine Johnson, Ms. Idonia Trotter, Dr. Suzanne Saccente, and Dr. Bob West.

Also attending: Senators Joyce Elliott, Linda Chesterfield and Representatives Andy Mayberry and Keith Ingram.

#### Opening Remarks by Senator Joyce Elliott

Senator Elliott called the meeting to order. She stated that the Task Force has previously discussed major issues such as the adult sickle cell clinic and funding sources for treatment. **Senator Elliott stated that after the Task Force hears the presentations about the clinic and funding sources it can decide what the legislative priorities are.**

Senator Elliott stated that she is not an official member of the Task Force, noting that in order to advance the Task Force initiatives other legislators have to get involved. Senator Elliott stated that upon request by Representative Reginald Murdock, Representative Andy Mayberry agreed to join the Task Force. She also informed the members that Representative Ingram had joined as well.

#### Approval of Minutes for August 1, 2012 [Exhibit C]

**Ms. Idonia Trotter made the motion to approve the minutes. The motion was seconded by Dr. Bob West and the minutes were approved.**

#### Sickle Cell Clinic Update

**Dr. Robin Devan, Assistant Professor, Internal Medicine, University of Arkansas for Medical Sciences (UAMS)**, was recognized and stated that she has a fellowship in palliative care and has worked the last four years treating sickle cell disease patients in the hospital. Dr. Devan commented that UAMS's palliative care division treats ten patients per month. She discussed the planning stages of creating the adult sickle disease clinic, noting that the planning stages are more significant than expected. UAMS is trying to determine where they are as a state and as an institution regarding the care of sickle cell patients. Dr. Devan noted that UAMS is planning a "hub" and "spoke" model of care for patients.

Dr. Devan submitted a handout entitled, "UAMS and Sickle Cell Disease" [**Handout #1**]. She stated that UAMS's #1 goal is to create a disease registry of every Arkansan with the sickle cell disease.

Dr. Devan stated that Arkansas Children's Hospital (ACH) does an excellent job with treating sickle cell patients up to age 21. ACH assists with setting up the patient with a primary care physician. Dr. Devan stated that UAMS needs to know how many sickle cell disease patients are in the state and where they live. Currently, Arkansas does not have a database or registry that identifies this information. After researching what other states are doing, Dr. Devan stated that there is a Center for Disease Control (CDC) initiative that has a registry of sickle cell disease patients. Nine states participated in this initiative and have written reports that are available online. All nine states

recommended that other states interested in creating a sickle cell disease clinic determine who the players are partners such as ACH and DHS-Medicaid that collects data. Dr. Devan noted that the nine states have a letter of agreement between the entities to link all of the databases to combine into one centralized database to better identify how many patients have the sickle cell disease, where they are located, and the providers within those areas.

Dr. Devan stressed the importance of creating a sickle cell disease patients' registry or database that shows the number of sickle cell patients in the state and where they live before the clinic gets completely off the ground, noting that this information can be educational and used as marketing tools that can be shown at legislative meetings, in commercials, schools, and at Community Health Centers (CHC). This would help the Task Force better target populations and communities. Ms. Trotter stated that this was one of the recommendations that came from the Task Force.

**Dr. Devan feels that two databases should be put in place prior to the clinic.** The first database would be for patients and the second one would be for the providers. Senator Elliott asked is there a specific process of finding out who the providers are. Dr. Devan stated that it is a slow process, noting that it took the other states' that completed the CDC project 6 months to get a letter of agreements between the entities to get up and running, noting that the states hired a data analyst to code, de-duplicate all the datasets into one database. Regarding the adult sickle cell disease clinic, UAMS will need a mechanism for de-identifying, cleaning, linking and de-duplicating several databases.

Dr. Devan stated that she will visit the CHC's to find the providers. She stated that creating the sickle cell disease patient database and providing a providers list could take up to one year to complete. Dr. Devan commented that everyone needs to be mindful of the Health Insurance Portability and Accountability Act (HIPPA ) regulations with regards to creating the sickle cell disease patient's list to ensure that it is de-identified, encrypted and password protected to respect the patients' privacy. Dr. Bob West stated that the registry that Dr. Devan has discussed is an open registry that is an updatable database that goes beyond what the traditional, classic public health registry does. Dr. West explained that the Arkansas Health Department (AHD) takes in data, sit on it, and processes it. The registry is not wide open to everyone. He stated that there would be advantages to UAMS being the chief keeper of the sickle cell disease data system, noting that AHD is willing to contribute newborn screening data and could possibly link the hospital discharge system to the registry if requested to do so. He stated that consent is a real issue in order to facilitate populating the database. Dr. Devan stated that other states used a letter from the state commissioner of health that gave the entities' investigators the authority to collect data on sickle cell disease patients for the purpose of establishing a patient registry. She stated that Arkansas could use this approach as well. Dr. Devan noted that some states also used a committee for the protection of human subjects to ensure that the program was in compliance with HIPPA. Dr. Devan noted that the two mechanisms were used by other states as opposed to a registry, noting that the information could be helpful to the legislature. Senator Elliott stated this information is instructive to the legislators and they may have to undertake with Dr. Devan's guidance.

Mr. Germaine Johnson asked how many sickle cell disease patients UAMS should be treating to be successful. Dr. Devan replied that in 2012, UAMS treated 40 sickle cell disease patients that visited the emergency room, inpatient center, and that were hospitalized that met the ICD9 code for sickle cell disease, noting that 9 of the 40 patients were seen multiple times. Dr. Devan stated that the average length of stay was 8 days. Dr. Devan stated that a systematic way to track the patients is needed, noting that 20% of hospital discharges for Arkansans with the sickle cell disease occurred in rural areas.

Dr. Devan reiterated that UAMS is committed to taking care of sickle cell disease patients across Arkansas. Regarding the clinic, Senator Elliott asked does UAMS have other needs to deal with in order to establish the clinic. Dr. Devan replied that UAMS has a lot of needs such as long-term funding for the clinic and buy-in from the legislature to ensure that the funds from the legislation is going to be maintained for the long haul.

Ms. Trotter asked how the funds issued by the Arkansas Minority Health Commission (AMHC) to UAMS, to assist with getting the clinic up and running are being used. **Mrs. Cherry Duckett, Director, Governmental**

**Affairs, Office of Administration and Governmental Affairs, UAMS**, was recognized and replied that AMHC committed to a gift of \$100,000 per year over a three-year period. The House of Representatives gave a gift of \$50,000 and the Governor's office matched their gift and gave a onetime gift of \$50,000 from the General Improvement Fund. Ms. Duckett stated that UAMS also had funds that amounted between \$20,000-\$30,000, noting that these funds were initially committed to looking at the viability of establishing the clinic. Ms. Duckett pointed out that all of the funds have been placed in an account to be used for relevant issues regarding the sickle cell disease clinic.

Ms. Duckett stated that UAMS has learned a lot from the Antenatal and Neonatal Guidelines Education and Learning System (ANGELS) Program (a program for high neonatal pregnancies). The program has evolved to having a Grand Round every week with all of the physicians participating from around the state. She stated that one of the biggest challenges that Dr. Devan has is an education, information element to physicians and caregivers in the state. Ms. Duckett commented that more physicians would be willing to do more, but they do not know what to do and how to do it. Senator Elliott asked what the challenge looks like. Ms. Duckett replied that the challenge is identifying a network of physicians and where they located.

Representative Ingram stated that the largest number of newborns are located in the Delta, noting that many individuals in this area migrate to Memphis for hospital care. He encouraged Dr. Devan to access this information by working with the Regional Medical Center in Memphis and the other three major providers there and include them on the physicians list. He noted that Shelby County has a very aggressive sickle cell program. Senator Chesterfield asked if UAMS could use the Memphis sickle cell disease program model to help facilitate and move the process along more quickly if we look at what is already in place around us rather than reinventing the wheel. **She suggested that the Task Force invite representatives from the Memphis hospital to be a part of their meeting agenda to discuss how they established their program and the things that are working well.** Senator Chesterfield concluded that members of communities that are most impacted by the sickle cell disease should be called upon to assist in the funding process. **Senator Elliott stated that the Task Force would look at the Memphis sickle cell disease program model.** She encouraged the UAMS representatives to be upfront with the legislators regarding the things that they do not have for the clinic. Mr. Johnson agreed to give Dr. Devan contact information for physicians that are currently treating sickle cell disease patients.

Upon request, Dr. Devan will give updates to the Task Force to keep them informed. She also requested each Task Force member's contact information to get their perspective on what each one feels is necessary to better the treatment of sickle cell disease patients in the state. She noted that most of UAMS's efforts are being placed on gathering information.

Ms Trotter asked could UAMS provide any future projection as to when the clinic would be up and running. Dr. Devan replied that she does not know at this point but tentatively projected that the clinic could be up and running in two years. She noted that a timeline and a plan would be discussed next week. **Upon request by Dr. Devan, Senator Elliott requested that committee staff add Dr. Devan to the Sickle Cell Disease Task Force interested parties notification list.**

Dr. Devan thanked the Task Force for inviting her to the meeting, noting that she is committed to the sickle cell disease project.

#### Waivers/Compensation for Care [Exhibit F]

**Dr. Andy Allison, Director, Medical Division, Division of Medical Services (DMS), Arkansas Department of Human Services**, was recognized and stated that Medicaid is a financing mechanism and DMS receives matching funds from the federal government with certain restrictions. The matching federal funds and state funds are used to reimburse medical providers for services that are provided to those that are eligible for Medicaid. With regards to the sickle cell disease waiver, Dr. Allison stated that if Medicaid's role has traditionally been financing, DMS wants to move beyond this role with the new Medicaid reforms and payment improvement initiative to more aggressively help patients and pay providers to manage the care of patients. He stated that if the Affordable Health

Care Act is implemented in Arkansas and the state chooses to expand the Medicaid program up to the 138% poverty level the percentage of sickle cell patients that are in the Medicaid program will increase.

Dr. Allison commented that the second largest payer for sickle cell disease care is Medicare, noting that DMS recently submitted an application to the federal government to participate in Arkansas' payment reforms; the movement to the patient-centered medical home and the movement to a health home. If the federal government chooses to participate fully with Arkansas in the multi-payer reforms it would give DMS a bigger vehicle to start looking at the sickle cell disease as an organizing principle for approaches like the health home and the patient-centered medical home.

Dr. Allison stated that Medicaid coverage for individuals that are brought into the program through the expansion may end up being different. The federal government has not given DMS final guidance regarding the nature of the required covered services under the Essential Benefits Package (EBP) in the Affordable Healthcare Act. Dr. Allison stated that the Affordable Health Care Act defines coverage before it provides it to individuals. This definition is for private health care insurance through the exchanges and tax subsidies that fund the expansion of private insurance coverage above 138% of the poverty level. The definition of coverage is called the EBP. The EBP is the minimum that a state can choose to provide to the Medicaid expansion. DMS does not know whether or not the minimum coverage is greater than the level of Medicaid services that are provided now.

Dr. Allison stated that Medicaid currently provides a hard stop limit of six prescriptions; three without an extension. He noted that the sickle cell disease is among many diseases that bump up against the limit. This complicates the granting of waivers because it immediately raises the equity issue of one disease verses another. The hard stop payment limit for hospitalizations is 24 days per year. Dr. Allison noted that hospitalizations beyond the 24 days would become an uncompensated care for the hospital.

**Dr. William Golden, Medical Director, Medicaid Health Policy-DMS, Department of Human Services,** was recognized and reiterated that the sickle cell disease was a very variable disease. Dr. Golden stated that DMS does not tell providers and physicians how to treat their patients however; their episodes of care approach allows for clinical variation. There are safeguards in place for the patients and providers for an unusual and highly complicated case. There is also a mechanism in place to support hospitals for uncompensated care at the end of the year. Dr. Golden noted that very few sickle cell patients exhausted the 24 days allowed for hospitalizations.

**Ms. Sheena Olsen, Assistant Director, DMS, Department of Human Services,** discussed the benefit limits for physician visits. She clarified that the Medicaid limitations that Dr. Allison discussed were for the adult population, noting that children do not have the same limitations. She stated that under Medicaid, adults have limitations of 12 physician visits per year however; the physician can request an extension of benefits coverage for the patient if he or she is seen by the physician.

Dr. Allison submitted a handout entitled, "Health Care Payment Improvement Initiative" **[Exhibit F]**. He stated that DMS's vision of Medicaid payment reimbursements in the future is not just a financing mechanism. It will help to pay for and direct coordination of care. DMS does not have a good handle on financing. As DMS moves to population-based or person-based payments as oppose to fee for service service-based payments, it may allow DMS to move away from the limitations that were described Ms. Trotter asked would it be possible to have the sickle cell disease waiver in order to move forward if the Medicaid expansion does not occur in Arkansas. Dr. Allison replied that DMS's commitment to moving ahead with the payment improvement initiative is independent of the expansion, noting that it needs to occur with or without the expansion. It is easier to achieve some of the system reforms with the expansion. Dr. Golden stated that if the expansion does not occur some adults would not be covered. He noted that Medicaid has financial challenges and there is a programmatic approach to providing benefits. DMS looks at services they will cover and make benefits determinations based on the information that is in the medical literature.

**Senator Elliott stated that the Task Force will need to invite physicians to discuss what things are on the ground to have a better understanding of how everything works.** For clarification purposes, Senator Elliott asked will DMS be moving ahead with the patient-centered type of funding in terms of using the \$100,000 gift in a different way with turning over the decisions to the patients and healthcare provider. Dr. Allison replied “yes” we are. He does not want to misrepresent any progress with the sickle cell disease in particular, noting that DMS would be listeners in that process, look for some cohesion in the recommended treatment, and address the variability and costs. He noted that these two conditions would allow DMS to move ahead with the sickle cell disease.

Regarding the Medicaid expansion, Senator Elliott asked would more individuals with the sickle cell disease be covered. Dr. Allison replied that everyone who is legal in the country should have affordable access and a source of coverage. Ms. Olsen stated that the Medicaid expansion is only part of the healthcare reform.

**Senator Elliott stated that a future meeting could be held at UAMS with agenda items to include pertinent testimony from physicians performing treatments and discussions regarding what they see as their drawbacks.**

**Senator Elliott stated that the Task Force needs to make sure that it is getting information and information reaction, noting that it would be helpful if the Task Force could triage its information. She asked that the Task Force members send their reactions and ideas from today’s meeting to Christean Bell to share it with Dr. Devan. She also requested that Task Force members send the names and contact information of physicians they know to her as well.**

Senator Elliott stressed the importance of electing a chair and vice-chair for the Task Force. Ms. Trotter stated that this is a critical time for the Task Force and the members are very committed. She noted that Senator Elliott has done a wonderful job and the Task Force needs the leadership from the legislature. She recommended that a legislator serve as either chairperson or vice-chair of the Task Force. **Senator Elliott stated that she and Ms. Bell will review the original legislation to determine if a legislator can serve as chairperson or vice-chair. If this is possible, Senator Elliott stated that a Task Force member should possibly serve as vice-chair.**

Senator Elliott stated that the next Task Force meeting date and new time will be Wednesday, November 7, 2012, at 10:00 a.m.

There being no further business, the meeting adjourned at 12:27 p.m.